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ABSTRACT

The newsletter article examines the impact of a handicapped child on siblings and offers parents suggestions for handling sibling relationships effectively. The article notes differences in the emotional adjustment process between older and younger siblings of a handicapped child. This report also explains typical sibling reactions of regression, acting out, and playing the "model child" role. The article encourages parents to be honest, find time for the nondisabled child, read books written for siblings of handicapped children with the nondisabled child, plan family meetings to discuss concerns, help the nondisabled child deal with reactions of friends, and join a sibling network. The report mentions some specific do's and don't's including: (1) "Don't isolate your family;" (2) "Don't overindulge the normal siblings;" and (3) "Do have siblings visit their disabled brother's or sister's school." Finally, the report provides references for 25 books appropriate for siblings and addresses of three sibling networks. (DB)

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★ Special Parent ★ ★ Special Child ★

Practical pointers for parenting handicapped children

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SIBLINGS



The presence of a handicapped child has an impact on the entire family. The increased responsibility and demands on time that accompany meeting the unique needs of the special child often disrupt and erode family ties. Siblings as well as parents frequently experience mingled feelings of concern, dismay and very often guilt. In this issue we will focus on easing the strain of having a disabled brother or sister and how parents can handle sibling relationships effectively so that each family member has the opportunity to function in a climate that fosters growth, compassion and bondedness.

Sibling relationships



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The older sibling. The knowl-
edge that the eagerly awaited new
baby has been born with problems
is so traumatic to the parents that
they frequently neglect the needs
of the older sibling. Parents mis-
takenly assume they are protecting
the siblings by avoiding or denying
the situation. However, parents
should be aware that all children
have a "sixth sense" and can often
tell by their parents' body lan-
guage, grim looks and preoccupa-
tion that something is amiss. The
fact that the birth of a baby sister or
brother has generated sorrow and
not joy is just as painful to the sib-
ling. Unless parents present the
facts as clearly as possible, siblings
not only worry needlessly, their
reaction to the baby's arrival is cast
with anxiety and fear. The medical
terminology used to describe the
baby's condition is frequently con-
fusing to the siblings and this too

can add to their apprehension.
Many siblings, for example, are
afraid they can catch their
brother's or sister's disability un-
less they are given clear-cut expla-
nations geared to their level of
understanding.

Often siblings hold irrational
fears that something they said or
did has caused the baby's disabili-
ty. An overlay of guilt thus clouds
their attitude towards the baby
right from the beginning.

New babies require much time
and attention even in normal cir-
cumstances. When the baby is
born with a disabling condition
even more care is required. Sib-
lings are apt to feel shunted aside
and even unloved. In later years
many siblings confide that their
earliest memories of their disabled
brother's or sister's infancy were so
filled with anger, worry or jealous
feelings, that they felt guilty about
having been born normal.



Sibling reactions

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The younger sibling. Younger siblings often fare better. Because the handicapped child was there first, the younger sibling has no adjustment to his entry into the family constellation. The routine of caring for the disabled child is usually firmly in place and thus the younger sibling does not perceive his handicapped brother or sister as a disruption. The younger sibling often considers his older

handicapped brother or sister as a playmate largely because their functional abilities are for a time equally matched. Even so, younger siblings will need concrete and simple explanations about the nature and outcome of their sibling's disability, especially as the younger sibling grows up and outdistances his older brother or sister.

In recent years studies have been conducted of siblings with a disabled brother or sister in an effort to document what behaviors or patterns of behavior can arise in the family. These basic reactions have been identified: reverting to illness, mimicry or regression; acting out; becoming a model child. On close examination, these patterns of behavior appear to be ways of seeking attention or approval.

Regression. Regressing to infantile behavior such as thumb-sucking, waking in the night, demanding to be spoon-fed or losing previously mastered skills such as toileting are all bids for attention and are demonstrations of feeling neglected. Mimicking the disabled baby's condition or symptoms is another sign that the sibling feels too much attention is being paid to his handicapped brother or sister. Some siblings become increasingly vulnerable to colds or other illnesses and even when ill for a legitimate reason cling to their symptoms longer than necessary. In this way, con-

sciously or unconsciously, they receive the care and nurturing that they yearn for.

Acting out. This type of behavior is difficult for families to handle and can run the gamut from pinching or picking fights with others—including the disabled brother or sister—to more serious forms of tantrums, truancy and outright refusal to conform to family rules. Lying, cheating and stealing are other serious behaviors that can arise.

Model child syndrome. This is the most difficult of all to identify as troublesome behavior. The sibling in many cases is subservient and becomes indispensable, taking over the burdens of child care chores, housework and other family obligations. Often, superhuman efforts on the part of the sibling are expended to achieve at school and sports activities as well. More likely than not, the over-achieving "model child" feels in some way that he personally has to make up for the pain and sorrow of having a disabled sibling. In fact the model sibling has become adept at masking or repressing his

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ambivalent feelings. Thus robbed of normal expression and in all probability feeling guilty, this type of sibling can only overachieve as a way of shoring up self-esteem or winning approval.

Often, grateful parents, relieved of some of their burdens, are unaware of the high price their model child is paying with his "adult" behavior.



Improving relationships



Parents of special children often find themselves in a no-win situation. Addressing the needs of their disabled child can lead to inadvertent neglect of the other children's legitimate bids for time and attention. Somehow by word or deed special parents have to convey the message that each child in the family, handicapped or accomplished, is a valuable human being capable of achievement and worthy of respect.

Here's how to help. The key to improving sibling and family relationships is honest and open communication. Often the non-disabled child feels embarrassed, jealous and resentful about his disabled sibling but has not been given the opportunity to express his true feelings. Help your child to vent his feelings. Put yourself in his shoes. Say for example, "You are feeling really angry about spending a vacation day having to go to the clinic with me and Jim." "I know we were planning to go to the beach and now we can't go. I'm disappointed too and I know how you feel." By listening to his feelings and interpreting events without anger or becoming judgmental you will be able to convey to your child that you understand and care.

Be honest. Talk about your feelings as openly as you can. Let your child know that you too are frustrated and even resentful at times. Tell him that you are also disappointed about plans that go awry and vacation days that are not pleasurable. Let your child know that anger and resentment are normal feelings for everyone and that the way to deal with them is to express these feelings without losing one's temper or acting out. Make alternative plans so that everyone has something to look forward to.

Find time so that your child feels he has your individual attention. This can be as simple as the two of you getting up 15 minutes earlier than anyone else to share an early-morning walk or chat together. Sharing these private moments alone with your non-disabled child validates his feelings and is often enough to defuse jealousy and resentment.

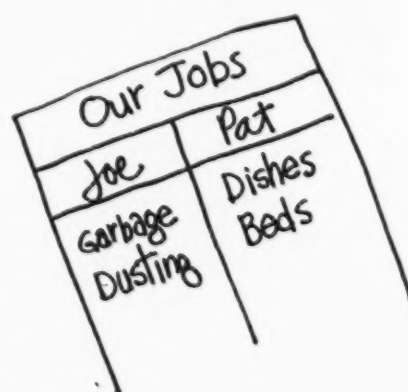
Read along with your non-disabled children books that have been specially prepared for the siblings of handicapped children. It helps to know that other children feel jealous or angry. It is always helpful to find out that others are in similar situations.

Plan family meetings where each family member can unburden himself or air problems without judgment or hostility. Learn to listen to each other. Seek ways to find out what the minor problems are before they become major issues. Decide together what's the best way for following family schedules and routines. Make sure the handicapped child in the family knows, understands and conforms to basic family rules and regulations as best he can. Nothing creates rancor more than unevenhanded discipline or rule bending for one and not the other. Special attention to the disabled child based on authentic need is one thing, special treatment is something else. "Peace at any price" strategies are bound to backfire. Allotting the handicapped child special privileges: allowing him to stay up later than others, for example, permitting him to take, misuse or destroy others' possessions or to tantrum and get his own way without discipline—guarantees siblings who will feel jealous, angry and resentful, and with good cause.

Maintaining consistent rules, on the other hand, makes every family member feel more of a participant. Involve the normal sibling in some of the day-to-day care of his disabled brother or sister as part of his normal routine. This will help the normal sibling feel involved, needed, even closer to his brother or sister without overburdening him. Taking on some but not all of the care will help the nondisabled sibling learn a good deal about his handicapped brother's or sister's condition and through this knowledge a greater understanding usually evolves.

Dealing with friends. Recognize that all children have an abiding desire to be accepted by their peers and in the parlance of child-

hood this means being just like everyone else. No one likes to be considered different and the presence of a handicapped sibling makes one quite different indeed. Siblings who query "What can I tell my friends?" or "Can't you do something?" are reacting to embarrassment. The best way to offset this is to recognize that people are embarrassed by things they don't understand. Children are often unthinkingly cruel and it will help if your youngster has information and facts at his fingertips about his disabled sibling's condition or symptoms that will dispel blunt remarks. For example, if friends tease and say things such as "Ugh, your brother drools," this can be countered with rational, matter-of-fact statements such as "Yes, my brother has a condition that interferes with his swallowing and we help him by patting his mouth to remind him to swallow." Encourage your nondisabled child to have his friends over. Let him introduce his handicapped sibling to his friends but don't let him interfere in their games unless invited. Make sure that your normal child is not expected to babysit his



Our Jobs	
Joe	Pat
Garbage	Dishes
Dusting	Beds



handicapped sibling at the same time his friends are over. Instead, allow the friends to gradually get used to the disabled sibling's presence. The more your child's playmates are exposed to the handicapped sibling in a nonthreatening, relaxed setting, the less likely they will feel embarrassed.

Opportunities should be provided for the handicapped sibling to be with his own peers, such as participating in Special Olympics, therapeutic horseback riding or recreational programs for the disabled. The handicapped sibling who is occupied by activities geared to his own needs will not have to be taken everywhere his normal sibling goes. Siblings can thus return to each other's company refreshed by this productive time spent away.

Join a sibling network. In re-

sponse to the unique needs of siblings with a disabled brother or sister, several specialized organizations have been formed that supply information, newsletters, conferences and events. Sharing experiences in a sibling group is in itself a form of support and should prove helpful.

Take heart. Parents with a handicapped child should not automatically assume that the siblings' lives will be ruined. If given the opportunity to function in an open, honest nurturing atmosphere, siblings can and do survive nicely. On the positive side siblings who have been raised with understanding have demonstrated greater maturity, sensitivity and are more resilient than the general population. Many eventually enter the helping professions: medicine, teaching, counseling.

Do's and don'ts

Don't isolate your family. Join a parent group. They are invaluable because no one else but someone who has been there can provide creditable support and advice.

Do be aware that sometimes professional counseling is necessary. Therapy is indicated if family members are experiencing depressions that continue for lengthy periods or if anger cannot be defused. The source of help should have training and sensitivity to the unique needs of the special family.

Don't expect your normal children to assume adult roles. This robs them of their own growing up experiences. Children who are overwhelmed with too much responsibility beyond their years have a tendency to be bossy and authoritarian.

Do have siblings visit their disabled brother's or sister's school.

Give them an opportunity to observe in the classroom or attend an open school night. Often siblings come away with a new appreciation of their brother's or sister's abilities and efforts.

Don't overindulge the normal siblings in an effort to "make up" for the fact that they have a handicapped brother or sister. This is misguided and only leads to confusion.

Do be aware that a certain amount of sibling rivalry is normal even when the child is nonhandicapped. Declarations of favoritism and cries of preferential treatment happen in all families.

Don't expect your normal children to excel in order to compensate for the disabled child in the family. This burdens them unnecessarily.

Sources of help

ATTENTION ALL READERS

We are currently in the process of compiling information about parent support groups so that we can share the information with readers seeking help. Please send us brochures or descriptions of any parent group or sources of help you know about.

BOOKS

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NETWORKS

Siblings Information Network
Department of Educational Psychology
Box U-64
University of Connecticut
Storrs, CT 06268
(Publishes newsletter for siblings, featuring articles written about siblings)

Siblings Understanding Needs (SUN)
Department of Pediatrics
University of Texas, Medical Branch
Galveston, TX 77550
(Publishes newspaper written by siblings)

Siblings for Significant Change
823 United Nations Plaza, Room 808
New York, NY 10017
(Information for families; for siblings events and services)